

Key Transitions for Adults with a Learning Disability: *Rapid Review*

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December 2025

Discussion Paper DP2025-01



THE LONDON SCHOOL
OF ECONOMICS AND
POLITICAL SCIENCE ■



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This NIHR Policy Research Unit (PRU) is part of the National Institute for Health and Care Research (NIHR) and hosted by the London School of Economics and Political Science in collaboration with the University of Kent and supported by King's College London.

This report is based on independent research funded through the NIHR Policy Research Unit in Adult Social Care, reference NIHR206126. The views expressed are those of the author(s) and not necessarily those of the NIHR or the Department of Health and Social Care.

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Acknowledgements

We want to thank a few people for their time and contributions in producing this review: Chris Hatton, Debs Smith and Raphael Wittenberg.

Wayne Marriott contributed to the project and the development of this paper. Wayne sadly passed away in 2025, before this paper was completed.

Executive Summary

Introduction

Formal services must provide a structured approach involving consistent support from skilled care professionals to allocate person-centred planning resources and identify suitable future accommodation options. Further research is essential to examine what works best for the transition of adults with learning disabilities to diverse formal adult social care and living arrangements.

Aims

The overall aim of the rapid review was to identify current evidence on the three key transition periods and to identify any gaps that could be explored further.

The review had a three-fold focus on:

- How are adults with a moderate or severe learning disability and family carers supported to make decisions about their care during a transition period?
- The understanding and implementation of the 2005 Mental Capacity Act (MCA) and the 2019 MCA amendment for young adults transitioning to adult services.
- The needs of people making these transitions, alongside the care and support they receive (including unpaid care and care services).

Rapid Review

A rapid review of evidence was conducted between October 2024 and February 2025, searching twelve databases from 1980 to the present and identifying peer-reviewed publications. The primary aim was to identify and gather evidence on key transitions for adults with a learning disability. Health-related studies were included if they had particular significance or saliency to transitions of people with learning disabilities to adult social care. Of the 1787 items initially identified by the literature search, and after applying the inclusion/exclusion criteria, a total of 12 articles were included in this review.

Conclusion

As the population of adults with learning disabilities grows older, there is an impending crisis for families. Increasing health, complex support needs and challenging behaviours of older adults with learning disabilities place pressure on ageing family carers to meet changes in care and support needs. Finding alternative care and appropriate accommodation becomes a priority when planning a transition to formal services. However, the health of carers and the burden of care often lead to crisis-driven placements, as there has been limited contact with services for this population to date (Local Government Association, 2021). Therefore, it became imperative to improve

transitions by preparing for adulthood at a younger age to engage adults with learning disabilities and their families with services (NHS England, 2018). However, this journey is marked by a lack of information, limited access to resources, no clear pathway and inconsistent planning from children to adult services to achieve these goals effectively. To navigate the process, families and carers become the primary advocates and voices in transition planning for young adults.

1. Introduction

Deinstitutionalisation in the UK began to take shape from the 1980s onwards, marked by key policy developments such as the Care in the Community initiative and influential government publications such as “Making a Reality of Community Care” (1986). These reforms signalled a shift away from institutional care towards supporting people with learning disabilities to live in the community. As a result, increasing numbers of individuals with learning disabilities now receive support in their own homes, often provided by family members or other informal carers.

More than 1 million adults with learning disabilities live in the United Kingdom (UK), comprising over 2% of the adult population (Office for National Statistics (ONS), 2019). Reflecting the trend of an ageing UK population (ONS, 2021), people with learning disabilities are also living longer. In England, an estimated 53% of adults with learning disabilities were aged 45 or older in 2020, with nearly 5% aged 85 or older; this demographic is projected to increase to 56% aged 45+ and 7.5% aged 85+ by 2040 (Institute of Public Care (IPC), 2020). This increased longevity significantly contributes to a projected 30% rise in the number of individuals with learning disabilities (LD) aged 50+ requiring social care services in England between 2012 and 2030. Annual growth in demand for adult social care services among this population is estimated to range from 2.0% to 2.7%, placing significant pressure on services to allocate resources across a broad spectrum of need, from mild to moderate, substantial and critical. (Emerson et al., 2012).

Adults with a learning disability must feel central to decisions about their care, including during key transition periods, to ensure they experience a smooth transition process in formal services. Practitioners play a vital role in this process and must clearly understand how to apply the Mental Capacity Act (MCA) during transition planning and assessment. Indeed, more complex cases require substantial consideration, and all practicable support should be offered to assist individuals with making their own decisions (Brown and Marchant, 2013). However, during this crucial time, there is limited evidence on how people with LD are supported. Where direct involvement is not possible and how professional stakeholders assess and use people’s preferences to inform best-interest decisions, there is little evidence exploring the understanding and implementation of the 2005 Mental Capacity Act (MCA) and the 2019 MCA Amendment, regarding transitions.

The Department of Health and Social Care (DHSC, 2001) placed independence, choice, inclusion and rights at the forefront of the *Valuing People* strategy for individuals with learning disabilities. The strategy acknowledged the longstanding issues with poorly coordinated services and planning. Although it prioritised young people at the point of transition into formal adult services, the additional funding made available at the time had a limited impact on improving resources (Cumella, 2008). *Valuing People Now* expanded its scope to include people with more complex needs and aimed to improve

the lives of all people with learning disabilities (DHSC, 2009). It emphasised person-centred transition planning and strategic improvements in care quality, choice and access, to enable young people to participate in their community and seek future employment. To address resource pressures, local authorities and the NHS increasingly commission services from the third sector, social enterprises and other community initiatives to support adults with learning disabilities in their local areas (Sheaff et al, 2024).

This review aimed to explore what is known about the needs, experiences, service interventions and resources for this population as they transition to different care contexts in the UK.

2. Aims

2.1 Review questions and objectives

Adults with learning disabilities must be central to decision-making through key transition periods when moving from children's services, leaving education and later in life when there are changes to current support mechanisms. However, there is limited evidence that has explored how people with a learning disability are supported using the 2005 Mental Capacity Act (MCA) and the 2019 MCA Amendment. It is important to ascertain how professional stakeholders assess and involve people to ensure that choice and preference are utilised to inform best interest decisions.

The overall aim of the rapid review was to identify current evidence and investigate three key transition periods, and identify any gaps that further work could explore, as set out below:

- Adults aged 17-18 receiving support through children's services and require support from adult services.
- Adults aged around 50 who are transferring from receiving informal family support to requiring formal support from adult social care.
- Adults aged 65 and over receiving support through adult social care services and require a change in support or are transferred to services for older people (for example, transitioning to a nursing or residential care home).

The review had a three-fold focus on:

- How are adults with a moderate or severe learning disability and family carers supported to make decisions about their care during a transition period?

- The understanding and the implementation of the 2005 Mental Capacity Act (MCA) and the 2019 MCA amendment for young adults transitioning to adult services.
- The needs of people making these transitions, alongside the care and support they receive (including unpaid care and care services).

3. Rapid Review

3.1 Methods

The UK Department of Health and Social Care (DHSC) defines a learning disability as '*a significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence), with a reduced ability to cope independently (impaired social functioning), which started before adulthood*' (DHSC, 2001). Internationally, the term intellectual disability is also used and is defined by three core criteria: lower intellectual ability; significant impairment of social or adaptive functioning, and onset in childhood (NICE, 2015). This review includes literature using both terms to ensure coverage of relevant research.

A database search was conducted from 1980 to Oct 2024 to identify peer-reviewed publications focusing on younger adults aged 19–24, adults aged 50, and adults aged 65 and over who are receiving support through adult social care services and require a change in support or are transferred to services for older people (for example, transitioning to a nursing or residential care home or sheltered housing).

International academic databases were searched as a primary resource. These included: EBSCOhost, PubMed, Web of Science, Scopus, PsychINFO, Social Policy and Practice, ERIC, Medline, CINAHL, ASSIA / IBSS. Databases were searched to identify whether a review had already been done. These included the Cochrane Library, the Social Care Institute for Excellence (SCIE) and PROSPERO. Citation searches, i.e. tracking articles that had cited a key article, snowball searching, and reference harvesting were also conducted as part of the review process.

Documents were selected for their relevance to the UK context of social care policy; non-UK literature was excluded. Any grey literature (discussion papers, working papers, government framework documents, policy statements and guidance documents) was excluded.

3.1.1 Search terms

3.1.2 Young adults

The following search terms (plus derivatives) were used as key words in the title/abstract: (transition) and (children to adult) and (learning disability), learning disabilities or intellectual disabilities or mental retardation or learning difficulties or special needs; young adults 19 – 24, transitional care or transition of care or care transition or discharge planning; young adults or adolescents or teenagers or college students; family caregivers or carer or carers, transitional or transitioned or transitioning, transitions, or supporting or supportive or supportiveness or support.

3.1.3 Adults aged 50

The following search terms (plus derivatives) were used as key words in the title/abstract: learning disabilities or intellectual disabilities or mental retardation or learning difficulties or special needs; adults aged 45 – 64; and adults or adult or aged or elderly or middle aged or older person; and carers or caregivers or family members or relatives or informal carers; and transition of care or transitional care or transition or transition or transfer; and change of care or change in social care needs, and community residential care.

3.1.4 Adults over-65

The following search terms (plus derivatives) were used as key words in the title/abstract: over 65s; ageing; growing older; transitioning; transition from home care to residential care; care transitions [pathways]; transition to residential care; changes in care (home to nursing) (domiciliary to residential) (continuity); change in social care needs; increase* dependency in older adults; adaptation of social care; long-term care; learning disability; intellectual disability; intellectual and developmental disability; community residential care.

Following the rapid review, no notable differences/influxes were observed in studies related to 18-year-olds coming into the Adult Social Care system at this point. Upon consultation with our Public Involvement and Engagement research advisors, we were advised that there might be an increased rate of young adults accessing adult social care support at age 25. This could result from accessing other support services through education, and this period of transition often coincides with the cessation of educational support services. Therefore, another search was conducted for this age range.

3.1.6 Young adults aged 25

The following search terms (plus derivatives) were used as key words in the title/abstract: learning disabilities or intellectual disabilities or (mental retardation); young people or youth or adolescents or young adults; young adults or emerging adults or young

adulthood; transitional care or transition of care or care transition or discharge planning; send or special needs or learning disabilities; local authority or local government or council; residential care or nursing home or long term care or care home; social care or social work or care homes or home care; community care or community setting or community or care at home.

A researcher reviewed the full texts of the remaining articles against the inclusion/exclusion criteria outlined in Table 1. Opinion pieces, such as letters to the editor or commentaries, were excluded from the formal summary and analysis.

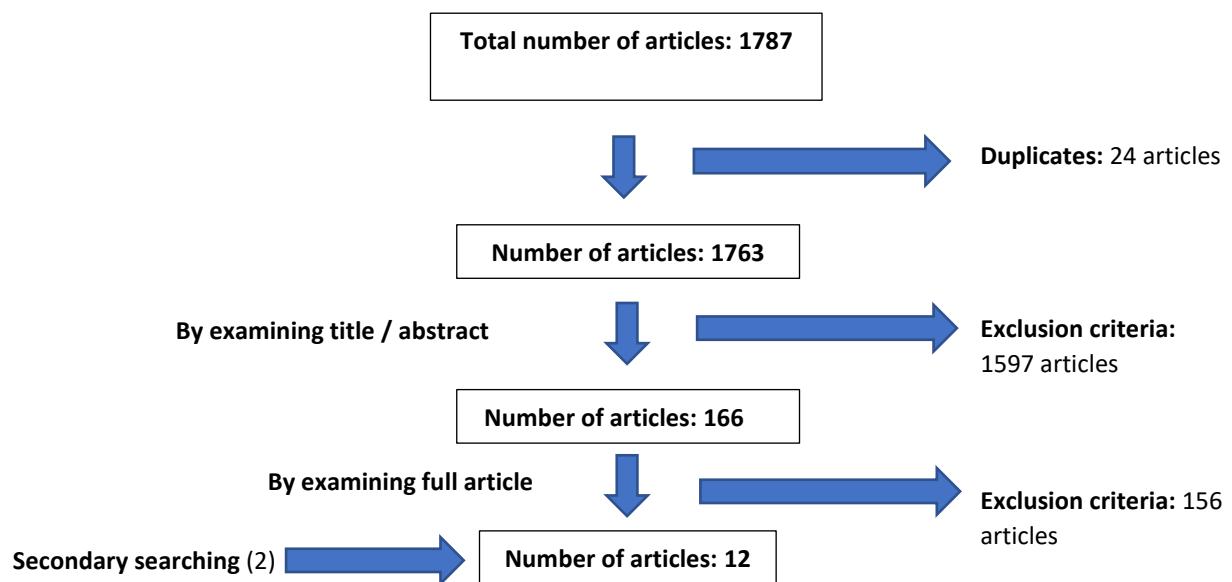
Table 1: Inclusion & Exclusion Criteria

INCLUSION CRITERIA	EXCLUSION CRITERIA
<ul style="list-style-type: none">• Literature written in English.• Studies conducted in the UK or if the UK is included in a larger study, findings/results are reported separately for the UK.• Publications from 1980 to the present.• Empirical peer-reviewed studies.• Studies focusing on key transitions for adults with a learning disability.<ul style="list-style-type: none">◦ Adults aged 17-18 receiving support through children's services and require support from adult services.◦ Adults aged around 50 who are transferring from receiving informal family support to requiring formal support from adult social care.◦ Adults aged 65 and over receiving support through adult social care services require a support change or are transferred to services for older people (for example, transitioning to a nursing or residential care home).• Formal diagnosis of learning disabilities and/or intellectual and developmental disabilities.• Studies focusing on adult social care support, e.g. residential care homes, group homes, supported/supportive living, assisted housing, shared lives, sheltered housing, extra-care housing, and core-and-cluster housing (i.e. number of independent flats in the same complex).• All research methods/designs.	<ul style="list-style-type: none">• Literature not written in English.• Non-UK studies.• COVID-related research.• Studies conducted before 1980.• Absence of a diagnosis of learning disabilities.• Non-adult population with learning disabilities (i.e. younger than 17 years).• Irrelevant aims and objectives of studies.• Studies focusing on clinical and healthcare services (e.g., psychiatric hospitals, general hospitals, ATU).• Studies using various populations/settings/variables, including those of interest, but they do not report their findings separately for the population/setting/variable of interest.

3.2 Results

The literature search is summarised in Figure 1. The review identified 1787 articles; 24 duplicates were excluded. A total of 1763 articles were excluded upon review of the title/abstract. After this screening, 166 articles were deemed potentially relevant to the research question and reviewed in full. Upon review of the full text, a further 156 were rejected based on the inclusion/exclusion criteria, mainly because they were not relevant. Two additional articles were included from a secondary search. A total of 12 articles are, therefore, included in this review.

Figure 1: Summary of literature search



A summary of the included review articles is presented in Table 2.

Table 2: Summary of review articles

Reference	Country	Participants	Sample	Key findings / Position
Anderson-Kittow, R. J., Keagan-Bull, R., Giles, J. & Tuffrey-Wijne, I. (2023).	UK	People with intellectual disabilities (aged 40+), parents and siblings.	36	<p>The study conducted interviews and focus groups with people with intellectual disabilities and their parents and siblings to understand perspectives and actions for future planning.</p> <p>The study found that participants understood they needed to make plans, but they did not feel supported. It concludes that person-centred resources and support are required for families to plan for transitions in care, including proactive approaches from social services and help to prepare for conversations with social care professionals.</p>
Barron DA, Molosankwe I, Romeo R. & Hassiotis (2013).	England	Young people aged 16 and 18 years with intellectual disabilities and challenging behaviour from one inner London borough.	27	Young adults with intellectual disabilities and challenging behaviour incur high costs to services and informal carers. The cost of informal care is double that of other comparable groups, such as those with dementia, where 33% of total estimated costs are attributable to informal care (Wimo et al. 2010). The article discusses the need for appropriate care packages for this group of young people.
Bhaumik, S., Watson, J., Barrett, M., Raju, B., Burton, T. & Forte, J. (2011).	England	Carers of young people (16-19) with intellectual disability.	24	The article reports on a study in the UK that explored the carer's perspective of the transition process to adult services and unmet needs and made recommendations on how to address these unmet needs. Recommendations are that integrated health and social care referral systems be developed with clear care pathways, and that individual and systemic outcomes be monitored. More support is required from carers outside the family, and the need for respite was also discussed.
Codd, J. & Hewitt, O. (2021).	England	Parents of young adults with an intellectual disability.	10	The study looks at the transitional process from children's services to adult services from the perspective of a parent of a son/daughter with an intellectual disability. The confusion parents face when their child with an intellectual disability/and or autism face when their child turns eighteen years old. Independence was key, particularly in how they enable their now-adult child to become more independent. It was discussed that there is currently insufficient collaboration and consistency from statutory services. It concludes that services must work together to better help parents navigate the adult care system. Writing better care plans which involve the person with an intellectual disability is important for a successful transition. More emotional support from intellectual disability services to parents is needed, and facilitating parent support networks was discussed. Also, simply recognising the role parents play is crucial.

Reference	Country	Participants	Sample	Key findings / Position
Furniss, K.A., Loverseed, A., Dodd, K. & Lippold, T. (2011).	England	Family carers, relatives and staff connected to people with Down's syndrome and dementia.	13	<p>A common theme from the family carers and relatives was the lack of information about the process of the diagnosis, symptoms and course of dementia and the services available to them. The theme Coping and Support reflected the impact of caring and what factors contributed to a positive or negative experience. The burden of caring for someone with dementia came through strongly. The theme reflected anxieties about the future for the person with dementia as the condition progresses and whether present care arrangements could be sustained.</p> <p>Family carers are not always parents and may be more likely to be siblings who have taken over the caring role later in life. This has implications for how services involve other family members in information giving and support. Family carers showed a strong sense of responsibility and commitment to caring for their family member at home, and a willingness to sacrifice their own needs to some extent. The emotional and physical strain on family carers and other members of their family was amply evident, heightened by the impact of night waking and the onset of verbal aggression and personality changes.</p>
Gilbert, A., Lankshear, G. & Peterson, G. (2008).	England	Older carers.	28	<p>Most considered residential care the only option and had no knowledge of alternatives; none had received or been aware of housing options or internet access. Most family carers (18) had considered, at some time, the future housing needs of their dependant when they became unable to care for them. For most, it was a background worry, but one they had difficulty confronting raised fears that no 'outside' care for their relative could be as responsive as themselves.</p> <p>Emerging Themes: Views on Residential Homes - many family-carers thought the only option open was for their son/daughter to go into residential care eventually. There were many negative comments about homes.</p> <p>Fighting 'tooth and nail' or 'Good as gold' – several family carers were grateful for the help received from social services, naming individuals who had been extremely helpful. However, several respondents commented about closures of residential homes, reductions in social service help and limited resources.</p> <p>Family input: Parents managed the current care of their dependant with little help from other family members. When it came to future care, some parents commented that one of their other children had offered to take on the care of their dependant.</p>

Reference	Country	Participants	Sample	Key findings / Position
Gillan, D. & Coughlan, B. (2010).	Ireland	Parent/carer participants.	12	All parents reported a range of negative elements in the transition experience. A range of barriers and facilitators were identified by parents that influenced the success of the transition and parental adjustment. Parents' reluctance to provide young adults with opportunities for independence, perceived vulnerability, and limitations was problematic. (1) a lack of information about available options, (2) a lack of "real" alternatives to the specialist vocational training provider, (3) waiting lists for available services, (4) lack of person-centred practices in vocational training service, (5) lack of coordination between child and adult services, (6) lack of parent involvement in decisions and planning, (7) problematic interactions with staff in adult services, and (8) vocational training staff "not listening" to parents.
Johnson, A. & Avery, C. (2022).	England	Young People who had turned 18 in the previous academic year.	67	The need for earlier planning was identified: inconsistent transition experiences across the county, a reduction of 8 social workers from children services to 5 in adult services, and a lack of information and uncertainty about the future. Bridging the gap towards better communication and working together, ensuring that safeguarding is integral to transition planning Recommended that transition service provides support, but there needs to be visibility and accessibility of service; earlier identification of those with emerging Mental Health needs, with earlier safety planning and preparation for transition.
O'Rouke, A., Grey, I.M., Fuller, R. & McClean, B. (2004).	Ireland	People with intellectual disabilities living in residential accommodation or with parents or guardians.	103 surveys (Carers / Guardians) 92 Interviews (people with intellectual disabilities or parents/ guardians)	Individual Interviews – 60 individuals with an intellectual disability were aged 40 -49; 32 were aged 50+. Living with family members was mentioned as a positive by 37 per cent of those who lived at home. Six people made general comments, for example, that they liked living with their family, while a further six commented on the availability of support. Seven people with an intellectual disability (39 per cent) who lived independently of the service reported difficulties with their families. Four people with a learning disability indicated that their family members were overprotective or denied them independence, while two said that their family members were impatient. Thirteen individuals with intellectual disabilities predicted a change in residence as they got older, either because of the death of their parents or through their personal choice. Two said they would like to live alone, two said that they would like to live with their siblings when their parents died, two wanted to live in a group home, and five wanted to live alone. One person indicated a desire to live in a nursing home when older, while two people said that they did not want to go to a nursing home. Carers' responses – individuals with learning disabilities residing at home were less likely to be viewed as appropriately placed than those living in residential locations.

Reference	Country	Participants	Sample	Key findings / Position
Prosser, H. (1997).	UK	Parent (s)/sibling carers of older adults with learning disabilities.	32	The overall conclusion of this paper is that adults with intellectual disabilities living at home with family carers can often face uncertain futures due to limited care planning. Only 28% of carers in the study had concrete plans for future residential care, leaving many at risk of crisis resettlement if primary carers could no longer provide support. Family care was widely viewed as the ideal, but concerns persist about the quality of residential options. Social workers are regarded as crucial in guiding carers through planning and encouragement to secure appropriate plans/accommodations. To support proactive planning, care professionals should be trained in the unique needs of ageing adults with intellectual disabilities and their families.
Shanahan P, Ollis L, Balla K, Patel R. & Long K. (2021).	England	Young people aged between 18 and 24 years with ADHD, ASD and/or ID. Family members were interviewed on behalf of the young person if the young person was unable to communicate with the researchers verbally.	10	Through semi-structured interviews, this study examined the experiences of young people (and their families) who had transitioned from children's to adult specialist healthcare services, rather than from the perspective of healthcare professionals. Four main themes were identified: (a) Parents as advocates, (b) Availability of adult specialists in health and social care services, (c) Lack of information sharing and (d) Transition as a binary, abrupt change. It was concluded that the services should understand and provide the coordination role now offered by parents in transition. They discussed the need for a patient-owned online information-sharing tool that includes information about relevant services for young people and their families.
Tilley, E., Jordan, J., Larkin, M., Vseteckova, J., Ryan, S. & Wallace, L. (2023).	UK	N/A	N/A	A rapid scoping review of transitions for older people with intellectual disabilities and behaviours that challenge others. The review aimed to explore what is known about the health and social care needs, experiences, service interventions and resources of and for this group. It found that consistent social work support, skilled staff, suitable accommodation, creative engagement with individuals and families to plan, and timely access to quality healthcare are all required to promote successful transitions as people age, and to avoid unwanted/inappropriate transitions at crisis point. It concludes that more research is needed to assess the types of services that this population can and do access as they age, the quality of those services, and how commissioners plan for this population.

4. Discussion and Implications of Review

4.1 Future Planning and Support for Adults with Learning Disabilities

The studies included in the review collectively highlight a significant gap in future care planning and support for adults with learning disabilities, living for the most part, with family carers. Many young adults transitioning from children to adult services experience fragmented and inconsistent planning, often leaving families to act as key advocates (Shanahan et al., 2020; Bhaumik et al., 2011; Codd & Hewitt, 2021). Parents frequently step in due to a lack of clarity, information, and coordinated support at age 18, with many reporting no clear pathway and insufficient access to resources to support independence.

For older adults with learning disabilities, increasing care needs and behavioural complexity also place additional strain on ageing family carers. Carers often lack clear information about prognosis and health changes, leading to misunderstandings and delays in seeking support. Negative prior experiences with services further discourage early engagement, contributing to crisis-led transitions (Furniss et al., 2021).

Housing and accommodation choices are central to enabling good quality community-based care. Suitable options are essential for maintaining relationships, reducing isolation, and providing continuity of support. Options include supported living, shared lives schemes, residential and nursing homes, extra-care housing, and independent flats (Gilbert et al., 2008; O'Rourke et al., 2004; Public Health England, 2019).

Despite the desire for control, choice, and independence, families often lack the guidance and resources to plan effectively. Few have concrete plans, leaving them vulnerable to reactive and potentially inappropriate transitions. As increasing numbers of older people with learning disabilities begin to outlive their parents, there is a growing need for formal services to step in (Prosser, 1996). Short breaks or respite services can help with phased transitions, allowing families to explore alternatives gradually and reduce the risk of crisis (Anderson-Kittow et al., 2024; Tilley et al., 2023).

Further research is needed to understand transitions into formal adult social care, focusing on service availability, planning effectiveness, and commissioners' preparedness to meet diverse needs. This includes understanding individual preferences and needs alongside implementing person-centred planning to avoid unplanned transitions.

4.2 Transitions for Young Adults Aged 16 to 25 Years

While 79.6% of people with learning disabilities aged 18 to 64 receive community-based services (NHS Digital, 2020), there is a noted shift to more formal support among those with complex needs. Ongoing analysis, combined with guidance from patient and public

involvement and engagement among lay research advisors with lived experience, suggests a notable rise in individuals entering adult services around age 25, often coinciding with the end of education-related support.

This review identified a lack of research specifically addressing the transition at age 25, despite the potential growth of service use at this point. The Connexions service, initially a national programme supporting young people aged 13 to 19 and those with EHCPs up to 25, is inconsistently available and, in some areas, has been replaced by the National Careers Service (Kaehne & Beyer, 2008). This inconsistency may contribute to service gaps.

Some studies describe a pattern in which young people enter training cycles without clear employment outcomes, leading to dependence on adult services (Cumella, 2008; Pearson et al., 2021). Parents often report limited options, inadequate communication between child and adult services, and a lack of alternatives. Some remain reluctant to promote independence, perceiving vulnerability and risk, while others take on strong advocacy roles (Gillan & Coughlan, 2010).

Health Education England (2016) outlines four domains essential to successful transition: social care, health, education/employment, and home/community. Effective transition requires person-centred, multi-agency planning starting from age 14 (NHS England, 2018; Johnson & Avery, 2022). However, only half of the services had accessible transition plans, often due to poor communication rather than language barriers (Bhaumik et al., 2011).

There is a need for tailored planning by geographic location, as service access and availability differ between rural and urban areas (Dunsmuir et al., 2020). Families continue to express concern about the lack of comprehensive, specialist services for individuals with complex needs. While post-16 colleges are standard placements, they often lack pathways to further opportunities (Kaehne, 2013; Hatton, 2017).

Transition planning should prioritise emotional wellbeing, relationships, and perceived autonomy. While parents are central to the process, their views on vulnerability can sometimes hinder efforts to promote independence. A balanced approach is needed to involve families while supporting young people's self-determination (Nguyen et al., 2024; Gillan & Coughlan, 2010).

Support levels vary by assessed need. Young people with more complex health and behavioural challenges often require frequent engagement with community and hospital services (Barron et al., 2013). Families assist in navigating these systems and play a crucial role in maintaining continuity of care (Codd & Hewitt, 2020).

5. Summary and Conclusion

This review identifies significant challenges across key transition points in the lives of people with a learning disability, particularly for those with higher support needs. Family and informal carers are often central to maintaining care until support needs increase, yet they frequently encounter barriers when attempting to access appropriate services.

The literature highlights the importance of early, structured, and person-centred planning supported by professionals who understand and can apply relevant legal frameworks, including the Mental Capacity Act (MCA) and the 2019 MCA amendment. However, there is a notable gap in evidence around how the MCA is implemented in practice during transition periods.

Key questions remain about preventing crisis-driven transitions through proactive engagement, better communication, and positive relationships with services. There is also a need to explore how formal services can better support ageing carers, deliver meaningful alternatives, and address future housing needs despite constrained resources.

The findings from this review have directly informed the development of the topic guide for the next study phase. This will explore how future planning and support are experienced and delivered by both families and professionals, with particular attention to key life stages, barriers and facilitators to successful transitions, and the role and practical application of the MCA in supporting choice and decision-making.

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